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EXPLORING FUTURE PLANNING SUPPORT FOR PARENTS OF ADULT
CHILDREN WITH INTELLECTUAL/ DEVELOPMENTAL DISABILITIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Patricia Alicia Lopez

June 2016

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ABSTRACT

For parents caring for an intellectually or developmentally disabled child (I/DD), there can be many challenges throughout various life stages. While research has been shown to emphasize an abundance of services for parents of young children and adolescents with I/DD, there has been a lack of services for later life transitions within adulthood. Within this research, a brief literature review of what preparation and services have been provided to parents of adult children with I/DD in regard to non-parental care placement is provided. The following research discusses the various perspectives of the future planning process through interviews from participants who identify themselves as a primary caregiver of their adult child with I/DD and who are 45 years of age or older. This research also discusses the results, limitations, recommendation for social work practice, and research conclusion.

Keywords: Intellectual or developmental disability (I/DD), non-parental care (NPC), Life-course perspective, future planning

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DEDICATION

I would like to dedicate this research to my uncle Angel Santos; you taught me the beauty of differences and embraced the world with an unconditional love that only a select few were privileged to witness. To you everyone was beautiful and everyone was good, and the world, my world at least, is a much better place for having received that kind of rare love. To my Grandfather Juan Santos, you have always been my protector, teacher, and example of what a good man should be. You always made sure that your “babies” had what they needed and always made sure that school came first; now that my academic journey has come to an end, I know that you are walking with me every step of the way saying “me too” . To the love of my life Ryan Merryman, you have loved me unconditionally through this journey and have been the best partner and support, I love you to the sun, stars and beyond. Finally, to my mom and dad, you blessed me with life and shrouded me with love which gave me the foundation of compassion and understanding that is so crucial in this kind of work and I can never convey how thankful I am for the both of you, I love you both.

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CHAPTER ONE

INTRODUCTION

Caregivers of Developmentally Disabled

For caregivers of individuals with intellectual and developmental disabilities (I/DD), there is often an increase of caring responsibilities and stress as a child transitions into adulthood (Dillenburg & McKerr, 2010). A caregiver can be defined as an individual who cares for a family member or friend who is unable to manage care for themselves due to frailty, illness or disability (Dillenburg & McKerr, 2010). An informal caregiver follows the guidelines of a caregiver, but in addition, has no expectation of monetary payment for their service (Dillenburg & McKerr, 2010). It is often the case that informal caregivers make up 82% of an I/DD adults support system (Dillenburg & McKerr, 2010). However, as an adult begins to transition into older age, there can be a decrease in supportive services due to isolation or financial barriers that can come with older age (Dillenburg & McKerr, 2010). This can lead to unique stressors in older age for both caregivers and those whom they care for, particularly stressors related to financial difficulties, declining health, becoming a single caregiver after the death of a partner, and the uncertainty of future care for the adult child with a I/DD (Dillenburg & McKerr, 2010).

Formulation of Problem

Problem Overview

There has been much research conducted on the services provided to families of children and adolescents with I/DD, however there has been little attention given to addressing the needs of the older population of caregivers and their adult children (Bigby, Ozanne, & Gordon, 2008). These needs can be vast and depending upon the level of care an individual with I/DD requires, and a parent can find themselves unprepared when the time comes to transition their adult child into non-parental care placement (NPC) (Bigby, Ozanne, & Gordon, 2008).

Specific Problem

While information can be provided to families regarding supportive services, it is currently unclear if older age caregivers are given the proper support to assist with transitioning their adult child into NPC or how effective current transition support is (Beralds et al., 2009). Many older caregivers often worry about the future care of their adult child in the event that they are unable to care for them themselves, and this can cause frustration and distress (Haley & Perkins, 2004).

Those Concerned with Problem

There are many groups that NPC supportive services may be of primary concern; however the group that may have the most concern for NPC preparation and programs would presumably be older aged caregivers who

are in progressively declining health or in the retirement age of 65 years and above (Parish, Rose, & Swaine, 2010; Perkins & Haley, 2010; Beralds et al., 2009). Other groups that may be concerned with NPC preparation are sibling caregivers, the Arc of California, aging and adult services, California Regional Centers and other professionals working with older adults and individuals with I/DD within the field of social work. Aging and adult services and California Regional Centers may have an interest in this project because it will be able to highlight what issues need further support for elderly populations and adults with I/DD transitioning into NPC. This can work as a preventative measure to reduce caregiver burnout, eliminate uncertainty of future care for an adult with I/DD and can prime available non-parental family members to care for their loved ones by providing relevant support and care options to sustain a good quality of life. Within the professional field of social work, further research of this problem is needed due to the predicted growth of the aging adult population to approximately 20.7% by the year 2050 (Heller, Caldwell, & Factor, 2007). The growing needs and barriers faced by the older population must be addressed early in order to improve services in the long term.

Importance of Further Understanding the Problem

Within the aging population of caregivers and adult children with I/DD, it is important to understand the barriers that inhibit caregivers to seek agency assistance or discuss information pertaining to NPC placement. Some caregivers may not be aware of services available to them or may have

apprehensions about giving up their caregiving role. Whether these issues are true concerns of caregivers, all barriers must be assessed in order to provide appropriate care to ensure the best quality of life for both the parent and the adult child. In a recent review of national literature, caregivers site that primary concern for future care of their child is their own declining health and previous negative experiences with services (Lunsky et al., 2014). Service accessibility, being informed of available services, and family focused services emphasizing an individual with I/DD and their family ability to maintain their independence is cited as most important to caregivers (Lunsky et al., 2014).

How this May Impact the Future of Social Work

This research has the potential to increase awareness amongst social service professionals by highlighting specific needs of older parents caring for adult children with I/DD. While connection with needed services is one portion of assisting a client in understanding their options for NPC, it is important for the social service professional to be mindful of developing a rapport with families before the concept of NPC can be discussed (Bigby, Ozanne, & Gordon, 2008). By providing caregivers with information early and prior to the transitioning process, caregivers can be given the opportunity to thoroughly think about what future care they would want for their child as well as involving the adult child in the decision making process so that transition can occur gradually and will be less of a shock when permanent placement is needed (Beralds et al., 2009; Bigby et al., 2008). This will allow social service

practitioners to maintain a sensitive approach to providing all services available to the individual with I/DD and their families (Lunsky et al., 2014). This will also ensure that social workers maintain an approach focused on integrating the whole caregiving family in supportive services that enable the family to design a future transition plan that is tailored to their needs, whether it is to transition into a residential form of care or supporting a higher functioning individual with community support so that they may maintain an independent way of life (Lunsky et al., 2014).

Research Question

Are elderly parents/caregivers of developmentally disabled adults given adequate resources and support to prepare for the time when the individual with developmental disability must transition into non-parental care?

Final Research Questions

After reviewing the information given within the literature, there are two questions that are important to research. 1) Does early connection with transition supports and resources alleviate caregiver worry? 2) According to caregivers, are social service providers effective in assisting future care preparation and supports?

CHAPTER TWO

LITERATURE REVIEW

Introduction

Through the literature reviewed, it has been found that parents of adult children with I/DD experience both joys and difficulties when caring for their child (Dillenburg & McKerr, 2010). Parents of adult children with I/DD often express feelings of stress due to their own declining health, financial constraints, and worry about the future care of their aging child (Dillenburg & McKerr, 2010). Within generations passed, many caregivers often did not worry about long-term care needs for those with I/DD because of an increased mortality rate due to susceptibility to illness. However due to great improvements in medical care, many individuals with I/DD are living longer and as a result, have a longer duration of care needs that must be met (Dillenburg & McKerr, 2010). Due to this extended lifespan, many caregivers often fall into the role of “perpetual caregiver” and can often find themselves having increased caring responsibilities as their child transitions from child specific services to adult services (Pilnick, Clegg, Murphy, & Almack, 2011). For example, once a person with I/DD transitions out of the schooling system in their adult years, particularly for those who face behavioral challenges or require constant supervision, many parents are left with a gap of time that they must now personally supervise (Pilnick et al., 2011). However, not all experiences by older caregivers are negative, and many express an

unconditional love for their child and a sense of expertise in their caregiving role (Dillenburg & McKerr, 2010).

Long-Term Financial Implication

One primary concern for elderly caregivers is the issue of financial stability and how this is affected by having to care for their adult child in a long-term capacity (Parish, Rose, & Swaine, 2010). Due to the high cost of health care, therapeutic services, special medical equipment, home modifications, and medical care, many older caregivers tend to work past retirement age in order to maintain financial stability (Parish, Rose, & Swaine, 2010). Depending on the child's I/DD, many families are forced to live off of one income because while one parent is working, the other parent must be available to care for their child's daily needs (Parish, Rose, & Swaine, 2010). Often times in home support only offers a limited amount hours for respite or outside professional care so this limits the job opportunity for the parent who is the main caregiver, which is often times the adult's mother (Parish, Rose, & Swaine, 2010). It has been found that while older adults tend to have a decent savings by retirement age, there are fewer "asset savings" to cushion their ability to recover from an unforeseen financial hardship such as an unexpected medical expense (Parish, Rose, & Swaine, 2010). The impact of a fixed income, fluctuating economy and cost of living also makes it difficult for caregivers to provide for themselves long-term and can place these individuals

at a greater risk for poverty and homelessness (Parish, Rose, & Swaine, 2010).

Compound Caregiving

Although it is assumed that a parent will care for their child with I/DD, the possibility of caring for other family members simultaneously can increase caregiver stress (Perkins & Haley, 2010). Depending on life circumstances, caregivers may find themselves caring for their elderly parents or their other non-disabled children while maintaining their responsibility of caring for their adult child with I/DD (Perkins & Haley, 2010). This can be difficult to cope with and can have particularly negative effects for their non-disabled children by consuming much of their time and attention (Dew, Llewellyn, & Balandin, 2004). Non-disabled children are at higher risk of feeling isolation from a lack of individual parental care (Dew, Llewellyn, & Balandin, 2004). However, non-disabled siblings are more likely to form a closer bond with their I/DD sibling and can be a great alternate support for socialization and involvement for their I/DD sibling (Dew, Llewellyn, & Balandin, 2004).

Sibling Taking Over Caregiving Role

Many factors can impact a parent/caregiver's decision to pursue NPC, however among many of the options provided, most caregivers opt to pass the caregiving role to another one of their non-disabled children. Often times this caregiving role is never formally discussed but is assumed that this transition

will happen when the parent caregiver is no longer able to care for their I/DD child (Coyle, Kramer, & Mutchler, 2014). This can place increased stress for the sibling because it has the ability to change their previously recognized sibling dynamic and can cause discord within the non-disabled sibling's already established home life (Coyle et al., 2014). Often time's non-disabled siblings are married with children of their own and are working to maintain financial stability (Coyle et al., 2014). While sibling involvement can vary from case to case, it is extremely important that these sibling caregivers are provided with increased support prior to and during the transition period so that caregiver burnout is less likely to happen (Coyle et al., 2014).

Need for Social Work Involvement

It has been observed within the literature that the involvement of the adult child with I/DD in the decision making process promotes a sense of autonomy and allows the individual to feel involved in the process (Pilnick et al., 2011). This can make the transition to NPC less stressful to the adult with I/DD and can create a sense of familiarity by knowing what will happen in the future (Pilnick et al., 2011). Social service professionals can assist with the preparation of NPC transition by ensuring that the family as a whole is knowledgeable of the future care plan in place. (Bigby, Ozanne, & Gordon, 2008). One important aspect of social service intervention is to allow the individual with the I/DD to play an involved roll in the transition process (Pilnick et al., 2011). Many I/DD's differ from one another, even within the same

disability spectrum (Pilnick et al., 2011). For example, an individual can have autism and have severe behavioral issues that prevent them from living on their own. Another individual with the same disability of autism may be able to care for themselves, have a job and be overall higher functioning with the capability to live independently. While these two individuals have the same diagnosis, they are very different in their independence level which should be addressed when seeking a NPC placement for adult children with I/DD (Pilnick et al., 2011; Beralds et al., 2009). It is also important for social service workers to emphasize that pursuing NPC does not mean that their child will be automatically placed into a facility; rather it gives the opportunity to address transitioning barriers (Beralds et al., 2009). Respite services are a good example of attempting to implement a transition of care at a less invasive level (Bigby et al., 2008). While respite services allow a caregiver some time to themselves, they also give the adult individual with I/DD some exposure to care from another person other than their parents (Bigby et al., 2008). These temporary changes in care can also enable the adult with I/DD to build social skills and broaden their social support (Pilnick et al., 2011). Although transition to NPC can be intimidating, it can provide caregivers with relieve from feelings of burden and guilt (Werner, Edwards, & Baum, 2009). NPC transition can often improve quality of life and for the family as a whole by reducing caregiver related stress and providing a strong support system so

that the caregiver can maintain a close and involved relationship with their child or sibling (Werner et al., 2009).

Gaps in Literature

One gap in the literature suggests that there is currently no research accounting for single parent caregivers and what long-term implications this can have for caring for a child with I/DD (Haley & Perkins, 2004). Another gap found in the literature is the impact that compound caregiving has on caregivers who are caring for their adult child with I/DD and assuming a parental role for their grandchildren. These gaps are important to understand and research further because they are each subgroups with specific needs that provide barriers to care and may cause further caregiver burden.

Methodological Limitations

Some methodological limitations found within the literature were a lack of an appropriate instrument that allows the information to be expressed from the I/DD individuals perspective (Beralds et al., 2009). There was also a lack of ability for caregivers to express what extra supports they would like to have available (Beralds et al., 2009). Lastly there was no specific instrument for younger elderly caregivers and older elderly caregivers to differentiate support needs. While all these older caregivers are over the age of 60, the support needs of a 60-year-old caregiver are very different from the support needs of an 80-year-old caregiver.

Past Theoretical Perspectives

Within previous literature, it has been shown that there are two primary theories (systems theory and life-course perspective) that explain the overall impact of change within the family dynamic, particularly when transitioning into NPC.

Systems Theory

This theory is defined as the interacting effects of different systems within an individual's life (Zastrow & Kirst-Ashman, 2013). Within this theory there is an emphasis on the interactions between members within a specific system, and what roles they play. The focus of this study will be on the family system and the support systems. As these systems intertwine, the roles are changed as one system is able to assist another. For example, when an elderly caregiver becomes unable to care for their child with I/DD and a non-disabled child intervenes, the role of caregiver is then switched from the parent to the non-disabled child and this can affect the family dynamic in terms of financial stability, caregiver stress and family structural change (Zastrow & Kirst-Ashman, 2013).

Life-Course Perspective

This perspective is defined as a continual change of human development that focuses on the impact of variations in an individual's age, life experiences, social context, culture, important life changes and individual developmental factors (Hooyman & Kiyak, 2011). Although life-course

perspective in more of a framework than a theory, it allows a greater understanding how a transition of care can impact a family as a whole (Coyle, Kramer, & Mutchler, 2014; Hooyman & Kiyak, 2011). This perspective also addresses the intersections between life transitions and their effects on the caregiving role, autonomy of the aging adult with I/DD and the sibling dynamic (Coyle et al., 2014).

Theories Guiding Conceptualization

Much like in previous literature, this study is guided by the same theoretical perspectives of systems theory and life-course perspective. These theories are important to this research because the perceptions of systems theory and life-course perspective best describe the impact of caregiver change and describe the overall impact on the family dynamic.

CHAPTER THREE

METHODS

Introduction

Chapter three provides a general overview of the study methodology. The study design, sampling procedure, data collection and intended instrument is discussed. Study procedures are also clarified and the protection of human participants during and after the duration of the study is addressed. Lastly, data collection and analysis is discussed.

Study Design

The purpose of this study is to determine if parents are given adequate support in the future-planning process of their child with I/DD. This study also assesses if parents are currently working with a social worker to help navigate through the future planning process. While previous studies focus on resources and support systems for school age youth with I/DD, there is currently little knowledge pertaining older age caregivers and their personal perceptions of future planning as it pertains to their adult child. In order to obtain the appropriate insight into the use of future planning resources and due to the personal nature of this study, a qualitative approach was used with the participants in this study. Qualitative data can be defined as “studies of subjects that are hard to quantify or interpretive research which produces descriptive data based on spoken or written words and observable behaviors”

(Grinnell & Unrau, 2013). While data gathering of this type can be important to research, the analysis of this data is essential in the data interpretation and would essentially render the data useless without appropriate interpretation by the researcher. According to Grinnell and Unrau (2013), qualitative data analysis involves coding the data set, dividing the text into small units and assigning a label to each unit and grouping these into codes and the codes into themes. This type of research begins in a broad view and is interpreted down into precise themes. Through implementing this approach in this research, the parents of adult children with I/DD were able to identify specific issues they face in the future planning process as well as elaborate their interpretation without any limitations of their perception of supportive services. This also allowed the participants the ability to address what supports they have found helpful, if they have already begun the future planning process.

The participants for this study were gathered through a snowball sample. In general, snowball sampling is a process where one individual is identified as a key individual in the target population. Initially, I facilitated contact with a key individual who is a parent of an adult child with I/DD; this individual then provided my information to other parents who expressed interest in participating in this research. Through conducting this research, various opinions on future planning services were observed. Participating parents identified their children as having various types I/DD and this resulted in differing needs. Some individuals identified their children as having a more

intensive I/DD diagnosis, while others had identified their children as fairly independent. These differences also impacted the data gathered by providing a wide spectrum of need perspectives.

Sampling

The sample of participants for this study consisted exclusively of parents who were caregivers of an adult age child with I/DD, at least 18 years of age. The parents consisted of individuals who were a minimum age of 45 or older and were caregivers of adult children with I/DD. The researcher's contact information was provided to one key individual in the older adult community who was initially interested in participating in this research. From this contact, other participants agreed to participate in this study and also agreed to pass on the researcher's contact information to individuals they thought would be interested in participating in this study. Once contacted, the research purpose was explained and, depending on if the participant wished to continue their participation in this study, the researcher collaborated on a time and place to meet with each individual in order to conduct the interviews. One participant requested a phone interview and they were mailed a packet which included the participant consent form and the demographic information page.

Participants were asked to fill out the information on the demographic form and sign the consent form. These items were then sent back in the paid postage return envelope provided. Once this information was received, the participant was then contacted by the researcher to set up an appropriate time

for the interview. On the day of the interview, the researcher discussed the informed consent and cleared up any last minute questions the participant had.

Data Collection and Instruments

The instrument used for this study consisted of a modified survey created by Benjamin T. Douglas. There was no email available for Mr. Douglas, however the researcher was able to contact him through a phone call. Mr. Douglas provided the researcher with a verbal consent on December 1, 2015, to use and adapt his interview tool for the purpose of this study. This survey had a demographic portion that the parent filled out upon coming to the interview or through a mailed copy. The second portion of this research was a face to face or phone interview consisting of questions that were asked after the participant completed the demographic portion. All participants were provided a 15-dollar Target gift card as gratitude for participating in this study. For individuals who participated in a phone interview, they were mailed a copy of the debriefing statement, resources, and 15-dollar gift card.

Procedures

This study focused on parents who have adult children with I/DD. Prior to beginning the interview, the participant was informed that they will be assigned a letter preceding the audiotape recording in order to maintain anonymity. Participants were then given the consent form to read and sign.

The participant was then given the demographic portion of the study to fill out prior to the interview. The participant interviews were audio recorded during the session and then were destroyed after the researcher's transcription of the interview data. Once the interview was completed, the participant was provided a debriefing statement about the purpose of the study and was given or mailed a debriefing statement, \$15 gift card, and resources addressing common future planning resources such as financial planning, other programs who offer family support, etc.

Protection of Human Participants

The protection of the human participants is of the utmost importance; each participant did not provide their name and were instructed to sign the informed consent with an "X" in order to remain anonymous. Each participant was assigned a letter in order to maintain participant privacy. Each participant was informed prior to being audio recorded and was assured that transcriptions would remain in a locked box for their privacy. Participants were informed prior that they were allowed to stop the interview during any time if they felt uncomfortable or wanted to stop the interview without any risk. All participants continued participation and none requested to stop the interview. The participant was given a form of consent prior to starting the interview and was provided information on resources from public information websites addressing common future planning resources such as financial planning,

legal planning, and other program information that offers support for their child and themselves.

Data Analysis

Data gathered through interviews rendered various trends and perspectives of caregiver support during the future planning process for their child. Many parents expressed a desire to “not think about” the future but also stated that they “know it is important”. Another theme that was observed was a variation in involvement of social services and social worker intervention in the future-planning process. The various themes found within audio and the transcribed data has been separated into categories of coding, category formation and classification. This will form themes and place importance in various factors of future planning and will be discussed further in chapter Four.

Summary

This chapter discussed a general outline and procedure of how this study was conducted. The expectations of the study’s findings in regard to parent’s perceptions of future planning preparation is addressed in chapter four, along with how social services currently assist with the future planning process. The study’s design, sampling, data collection and instruments were described. Procedure and debriefing of participants’ pre and post study were also discussed.

CHAPTER FOUR

RESULTS

Introduction

This chapter provides results of this study regarding future planning support for parents of adult children with intellectual/ developmental disabilities. The results of this study have been categorized into the following six segments: demographics, social service professional supports, future planning discussion, decision making process, anticipated supports, and concerns of care. Each segment discusses responses from eight participants and includes direct participant information as well as direct quotes.

Results

Demographics

Parents. All Participants were assigned a letter from A to H, and each participant was referred to by their assigned letter. Within this study, there were eight participants consisting of two male participants assuming a caregiving role and six female participants assuming a caregiving role. Five participants identified themselves as Hispanic in ethnicity, one participant identified as Caucasian in ethnicity, one participant identified as both Hispanic and Native American in ethnicity, and one participant declined to answer. All participants were within the desired 45 and above age bracket for this study and their ages ranged from 49 to 65. In regard to education level, four participants identified themselves as having “some college”, two participants

identified themselves as a “high school graduate”, one participant identified as having a “bachelor’s degree” and one participant identified as having “less than high school” education. In regard to marital status, 6 participants identified themselves as being “married”, one participant identified as being divorced, and one participant identified as being single. In relation to current health, 62.5% of participants identified themselves as being in “very good” health, 25% of participants identified themselves as being in “just ok” health, and 12.5% participants identified as being in “poor” health.

Adult children. In regard to their child with I/DD, all participants identified their children as adults, ranging in ages between 22 to 46. In regard to their child’s I/DD identification, there was a mixed result among participants. Four participants identified their child as having multiple diagnoses (at least two or more) of the following: autism, cerebral palsy, epilepsy, and occipital encephalocele. Two participants identified their child as having autism, and two participants identified their child as having Down syndrome (Trisomy 21). In regard to health, 50% of participants identified their child as being in “very good” health, 12.5% identified their child as having “just ok” health, 12.5% of participants identified their child as being in “fair” health, and 25% of participants identified their child as being in “poor” health.

Social Service Professional Supports

All participants reported that they currently receive some form of support from an agency and are currently or have been in contact with a social

service professional while working with an agency or program. When asked what assistance programs they are connected to, all participants reported that they receive services through a Regional Center in their area. For seven of the eight participants, their adult children additionally received Medi-Cal, Supplemental Security Income (SSI) and In-home Supportive Services (IHSS) hours; one participant was in the process of obtaining SSI and Medi-Cal for their adult child.

While all participants expressed gratitude for the services they received through Regional Centers, it was found that participants had mixed experiences with obtaining services for their child, with 75% expressing that they had a positive experience with obtaining services and 25% expressing they had a negative experience with obtaining services. For example, Participant B stated,

The services are there, but it's just my lack of moving forward. I'm thankful for Regional Center, I'm thankful for in-home Services because in the beginning when I knew nothing about my daughter's illness and how she was going to be affected and how we were going to be affected as a family, Regional Center was there, and while she was still in the hospital, they were the ones who helped guide us and walked us through the process which was very very helpful... I'll never forget that. I remember feeling like what am I going to do with this child, I don't know what to do and they guided us and I felt a lot better once I knew who to

talk to and to contact. That was great so, I'm very very grateful for the services that my daughter receives. (Participant B, Personal Interview, March 2016)

While six out of eight participants expressed that the resources they currently have for their child are accessible, for the two other participants, navigating through services has been a difficult process as shown by the statement by Participant C,

...our caseworker at Regional Center is pretty good, that's not always the case, it's a mixed bag with people from over there. Um, she basically answers any questions that we may have...there's nothing out of the blue that's offered, we found exactly the opposite working with them, all of this is you "have to know yourself" because Regional Center is notorious for not telling you things. When we first got Regional Center Services they actually bragged to us, that this Regional Center here in San Bernardino paid less per client than any other Regional Center in the state of California. They thought that would really impress us, no it doesn't impress us. I mean why would we be happy that, that they are not spending money on their clients? (Participant C, Personal Interview, March 2016).

Future Planning Discussion

Pertaining to the discussion of future planning, seven of the eight participants did not involve their child with I/DD in the discussion of future

planning due to their child's perceived inability to understand this concept. For example, Participant A stated, "My daughter has no communication skills, she's basically a 2-year-old mentally and doesn't comprehend a lot of concepts and one is future planning; so she has no clue. For her, it's just keep her fed, dry and she's fine" (Participant A, Personal Interview, March 2016). Similarly, Participant F responded with a comparable answer, stating "No I haven't talked to him about it because my son doesn't speak and he wouldn't understand that concept" (Participant F, Personal Interview, March 2016). One participant, Participant G was able to have a conversation with their adult child about their future plans and was able to have him involved in the process stating,

So yeah we're just trying to get him ready to be independent because the Pomona Regional Center has a program, when he does want to move out, they can help him with living classes where they show him how to do banking, groceries shopping, cooking, transportation, and they help him with benefits and he wants to learn... We've talked to him about, you know the importance of keeping up with his Dr.'s appointments and making sure that he knows he has to ask for things.... You know, there's a lot of people who are very severe and my son is called I guess high functioning, so there is some people who can't take care of themselves and they live in group homes, and there are some people like my son who can learn life skills and live

independently and I love that he's going to have a job with the Department of Rehabilitation so that's great! (Participant G, Personal Interview, March 2016).

While all participants agreed that planning for the future was an important task, only three participants have sought out and had a conversation with a social service professional about finding services in regard to future planning. For example, Participant D stated

The caseworker that we get the most information from would be Inland Regional Center, and she, when we actually started to place him before, she actually got placements... She's connected us with transition programs, with day programs for him, so we have discussed that before, but the family just wasn't ready at the time and we want to keep him with us as long as we can. (Participant D, Personal Interview, March 2016)

The other five participants stated that they have mentioned plans to family members in passing, but have had no formal discussion with an agency as to what steps to take for the future planning process. For example, Participant E stated "when I am deceased, I will send my daughter to El Paso Texas to live with my 6 sisters, but there is nothing in writing, it's just an understanding we have" (Participant E, Personal Interview, March 2016).

Additionally, when participants were asked what information or aid has been provided to them in regard to future planning, all participants stated that

they had been given resources and assistance for current care, but no resources addressed planning for the future unless they initiated the conversation. Three participants stated that they initiated the future planning conversation regarding services for conservatorship, housing options, and legal aid; while the other five participants did not initiate the conversation because they had formed their own plan and some expressed a reluctance to discuss the topic. For example, Participant B stated “I know our family would take care of her, but I think that I push it to the side as if it isn’t going to happen; but I know it’s necessary and that’s why I’ve taken steps to alleviate that problem” (Participant B, Personal Interview, March 2016). A similar response was provided by Participant F stated “you know parents always think that we’ll always be there for our kids, but it’s just not the reality one day I can pass and he will live and we have to think about that” (Participant F, Personal Interview, March 2016).

Decision Making Process

Within the decision making process, participants were asked to discuss who will make decisions for their child in regard to living arrangements, financial decisions, and health decisions. While all participants want their child to remain in family care for as long as possible, participants had mixed reviews on who will assume decision making authority after they are no longer able to care for their child. Decision making authority was broken down into three categories of sibling decision maker, extended family decision maker, and

independent decision maker. In regard to overall decision making, five of the eight participants wanted their child's sibling to assume decision making authority, two participants wanted extended family caregivers to assume decision making authority, and one participant wanted their child with I/DD to assume his own decision making authority. While the majority of participant's wanted their other children to assume decision making authority for their child with I/DD, six out of eight participants did not want their children without I/DD to assume a primary caregiver role for their child with I/DD and preferred that their child with I/DD live with another family member or was placed in an appropriate alternate housing option. For example, Participant D stated

We will be in charge of that because we do have conservatorship, co-conservatorship, so we make the decisions until we can't anymore and eventually if he survives that long and we're not here anymore, then my daughter will have to take over. I imagine eventually, she will have to file for conservatorship unless she decides not to, I've told her you should not have him living with you because I want you have a normal life sometime in your life. She hasn't had a normal life my son was diagnosed when I was like six months pregnant with her, so yeah we don't want that. (Participant D, Personal Interview, March 2016)

Similarly, Participant G stated,

...my husband and I were like hey we're getting older, he needs to be independent, and we don't want his brother and sister to be responsible

for him so that's when we got connected to Pomona Regional...my son and daughter are very protective of him they are very good and they understand, they know that there are going to be times where they have to be there for him and help him, but we want our son to be independent so he can achieve what he wants in life and he can be independent, maybe learn how to drive one day, like everybody buy a home, have a job, have a girlfriend, you know have a family, whatever he wants to do. (Participant G, Personal Interview, March 2016)

Anticipated Supports

Overall, all participants assume that future supports will be available to their child in a variety of ways, however the most important future supports that parents wanted for their child was continued family support and program involvement for their child when they are no longer able to provide care for them. For example, Participant H stated

he has family that loves him very much and his work they really love him and he has a lot of friends when he goes there, and you know he'll have his cousins and aunts, he comes from a large family a very large loving large family...I don't know what better services there could be, I just want that he has his own room and that he keeps going to his programs. (Participant H, Personal Interview, March 2016)

Similarly, Participant F had a similar response stating "I'd like him to keep participating in the programs like he is right now and maybe start going to

activities and places, you know where they keep them busy and take them to exercise and dance he loves music” (Participant F, Personal Interview, March 2016).

Concerns of Care

Within the research presented, concerns of care that were expressed generally varied across participants. 25% of participants were concerned with the quality of care their child would receive and the other 62.5% of participants were concerned with maintaining stability for their child once they are no longer able to care for them and 12.5% of participants reported having no concerns due to having family members caring for their child. For example, participant C cited a quality of care issue stating,

...we don't trust anybody in these facilities and I'm not saying these people are bad, but they're paid no money, and you go into these facilities and they're not the cream of the crop of people. I mean they're whoever they can get, nobody wants to care for kids like this! It's, it's not a pleasant job to do, so they hire whoever they can get and you know, you hear the horror stories about abuse in these facilities. So that would be my primary concern that's, that's the main thing that keeps us from placing him somewhere. Nobody's going to care for him like we care for him; neglect and abuse are our main concerns. (Participant C, Personal Interview, March 2016)

In regard to maintaining stability for their child, many participants expressed a concern for desired caregiver availability rather than quality of care. For example, Participant A stated “That the individuals we want to care for her are not available or cannot assume care for various reasons and she end up in an institution, that’s our nightmare. We would never want that, we would never want her to be institutionalized or put in a home, it’d be like placing an infant in a home, that’s what it’d be.” (Participant A, Personal Interview, March 2016)

Conclusion

Within this chapter, results of this study regarding future planning support for parents of adult children with intellectual/ developmental disabilities were presented. The results of this study were taken from a sample size of eight participants and their demographic information as well as their interview answers were presented in six separate classifications consisting of demographics, social service professional supports, future planning discussion, decision making process, anticipated supports, and concerns of care. Results will be discussed in greater detail in chapter five.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will present a discussion of the results found in this research study detailing future planning support for parents of adult children with intellectual/ developmental disabilities, as well as present study limitations and recommendations for future social work practice. This chapter will also discuss what implications this research has for social work policy and future research. This chapter will conclude with an overall review and understanding of the study in its entirety.

Discussion

From the results presented in the Data Analysis, this study found the following key findings: perpetual caregiver role, siblings caregiver role, future planning support by social service professionals, lack of formal documentation, and involvement of I/DD child in decision making process.

Perpetual Caregiver Role

In regard to caregivers and their role in perpetual caregiving, this study found that all participants, whether working or not, maintained a caregiver role well into their child's adulthood. While some parents were able to facilitate some independence for their child (such as work programs and life skills preparation programs), all parents remained the primary caregiver for their child and experienced a greater need for services that offered caregiver

assistance for those parents who had children with greater needs. This finding is consistent to the findings provided in the literature indicating “many caregivers often fall into the role of “perpetual caregiver” and can often find themselves having increased caring responsibilities as their child transitions from child specific services to adult services” (Pilnick et al., 2011, p. 303).

Sibling Caregiver Role

In regard to sibling caregivers, this study found that most participants did not want their other children to assume a caregiving role for their sibling with I/DD. These findings differ from the literature that indicated

Many factors can impact a parent/caregiver’s decision to pursue NPC, however among many of the options provided, most caregivers opt to pass the caregiving role to another one of their non-disabled children. Often times this caregiving role is never formally discussed but is assumed that this transition will happen when the parent caregiver is no longer able to care for their I/DD child. (Coyle, Kramer, & Mutchler, 2014, p. 303)

While all parents described their non I/DD children as having close relationships with their sibling with I/DD, which is consistent with the literature indicating “non-disabled siblings are more likely to form a closer bond with their I/DD sibling and can be a great alternate support for socialization and involvement for their I/DD sibling” (Dew, Llewellyn, & Balandin, 2004, p. 177), most wanted their non I/DD children to provide support for their sibling with

I/DD in regard to decision making assistance rather than providing housing and permanent caregiving.

Future Planning Support by Social Service Professionals

In regard to social service professional support, it was found in this study that future planning conversation and resources are not provided by social service professionals unless the services and resources are requested by the parents of children of I/DD. While previous literature provided benefits of future planning, as indicated by “Social service professionals can assist with the preparation of NPC transition by ensuring that the family as a whole is knowledgeable of the future care plan in place” (Bigby, Ozanne, & Gordon, 2008, p. 27), many professionals do not provide future planning resources until times of need which can often during times of stress and crisis.

Lack of Formal Documentation

In regard to formal documentation, within this research, none of the participants had any formal documentation of a plan in place for when they are no longer able to care for their child with I/DD. While previous literature reviewed did not directly address any formal documentation for future care, literature highlights the benefits of having a plan in place as indicated by “Social service professionals can assist with the preparation of NPC transition by ensuring that the family as a whole is knowledgeable of the future care plan in place” (Bigby, Ozanne, & Gordon, 2008, p. 27). Many participants in this

research indicated that they had an informal plan in place that depended on other family “stepping in” when that time comes.

Involvement of Intellectually/Developmentally Disabled Child in Decision Making Process

The last finding within this study was the perspective of parents not involving their child with I/DD in the planning process. Within previous literature it was found that

involvement of the adult child with I/DD in the decision making process promotes a sense of autonomy and allows the individual to feel involved in the process. This can make the transition to NPC less stressful to the adult with I/DD and can create a sense of familiarity by knowing what will happen in the future. (Pilnick et al., 2011, p. 304)

However, this study found that depending on the child with I/DD’s perceived cognitive ability, many parents did not feel that their child would be able to participate in the decision making aspect of future planning. While social service professionals can help facilitate future planning process conversation, this conversation is delicate and must be presented in a thoughtful manner that addresses the wants and needs of the family, as shown by the literature indicating “It is also important for social service workers to emphasize that pursuing NPC does not mean that their child will be automatically placed into a facility; rather it gives the opportunity to address transitioning barriers” (Beralds et al., 2009, p. 170).

Limitations

There are three primary limitations of that were observed within this study. One limitation to this study was the small sample size, consisting of only eight participants. The interviews and viewpoints from participants given in this study are not a general consensus of the larger population and is reflective of a limited experience and understanding of the future planning process.

Another limitation to this study was the variation of participants that participated. Most of the participants involved in this study had children with I/DD who were diagnosed with severe daily functioning and medical needs; as a result, this may have influenced the outcome of future planning needs in regard to parent's perceptions of their child's involvement in future planning.

The final limitation in this research was that participants were gathered through a snowball sample and the quality of participants could have been influenced by the gatekeeping of the key referring individual of this study.

Recommendations for Social Work Practice, Policy, and Research

One recommendation that would be helpful towards social work practice would be for social workers and social service professionals to have an open dialogue with families and caregivers about what future planning is and normalizing the discussion so that caregivers would feel more comfortable with having the conversation and would not associate this transition with caregiver guilt. Another recommendation would be that further research should

be conducted in the future regarding the parent's perspective of sibling caregivers. It is currently unknown if this difference in the literature and the research conducted in this study is due to a paradigm shift in caregiving perceptions or if this difference is attributed to the type of participants within this sample; a larger future sample would be needed in order determine a cause for this change.

Conclusion

This chapter has discussed the key findings of this research, presented an interpretation of the data, and discussed the needs for future recommendations to be addressed. The key findings presented pertained to the perpetual caregiver role, siblings caregiver role, future planning support by social service professionals, lack of formal documentation, and involvement of I/DD child in decision making process. This chapter also discussed possible future research that needs to be addressed in order to improve the field of social work for this protected group.

APPENDIX A
QUESTIONNAIRE

QUESTIONNAIRE

Please fill out the paper below and hand it to the interviewer after you are finished

1. What is the gender you closely identify with?

- ☐ Male
- ☐ Female
- ☐ Other

If you answered other, please specify how you identify

2. What is your current age? _____

3. How many total children do you have? _____

4. How many with an intellectual or developmental disability? _____
What is the age(s) of your child(ren) with an intellectual or developmental disability?
-

What type of specific intellectual or developmental disability does your child(ren) have?

5. What is the ethnicity you most closely identify with? (Please check all that apply)

- ☐ African American/Black
- ☐ Hispanic/Latino
- ☐ White/Caucasian
- ☐ Asian/Pacific Islander
- ☐ Other

If you identify as other, please specify the ethnicity or ethnicities you identify with:

6. What is your highest level of education (Please check one)

- ☐ Less than High School
- ☐ Bachelor's Degree
- ☐ High School Graduate
- ☐ Some College
- ☐ Master's Degree or more

7. Including you, how many people are currently living in your home? _____

8. How many people assist you in the care of your child with an intellectual or developmental disability? _____

9. What is your current marital status? (Please check one)

- ☐ Single
- ☐ Never Married
- ☐ Divorced
- ☐ Married
- ☐ Widowed
- ☐ Cohabiting (living together, but not married)
- ☐ Other

If you identify as other, please specify how you identify

10. How would you characterize your current overall physical health?

- ☐ Excellent
- ☐ Very Good
- ☐ Just ok
- ☐ Fair
- ☐ Poor

11. How would you characterize the overall health of your child(ren) with an intellectual or developmental disability?

Child 1

- ☐ Excellent
- ☐ Very Good
- ☐ Just ok
- ☐ Fair
- ☐ Poor

Child 2

- ☐ Excellent
- ☐ Very Good
- ☐ Just ok
- ☐ Fair
- ☐ Poor

Child 3

- ☐ Excellent
- ☐ Very Good
- ☐ Just ok
- ☐ Fair
- ☐ Poor

I'm now going to ask you a series of questions about your future plans for when you can no longer provide care for your child with an intellectual or developmental disability.

Interview questions

1. In regard to your child, what assistance programs are you connected to?
2. Have you thought about or began the process of future planning for your child?
3. If you are currently working with a social worker, what information or aid have they provided to you in regard to future planning?
4. If you are not working with a social worker, who is helping you find assistance or information on the future planning process?
5. What have you discussed with your child in regard to future planning?
6. If you have not yet discussed future-planning, can you tell me some of the reasons why you have not had the discussion yet?
7. If you could no longer provide care for your child, what sort of living arrangements would be ideal?
8. If you could no longer provide care for your child, how will financial decisions be handled?
9. If you could no longer provide care for your child, how will health decisions be handled?
10. How much assistance will your child receive from social supports, including family, friends, religious or community programs?
11. What is your greatest concern for your child when you can no longer care for him/her?
12. What is the best possible situation for your child when you can no longer care for him/her?
13. What additional services, if offered, would better prepare you to plan for the future of your child?

Thank you for your time and participation in this study.

Adapted from Douglas, B. T. (2009). *Permanency planning for adults with developmental disabilities living with their parents* (Order No. 1466096). Available from ProQuest Dissertations & Theses Full Text: The Humanities and Social Sciences Collection. (305178664). Retrieved from <http://libproxy.lib.csusb.edu/login?url=http://search.proquest.com/libproxy.lib.csusb.edu/docview/305178664?accountid=10359>

APPENDIX B
INFORMED CONSENT



California State University, San Bernardino
Social Work Institutional Review Board Sub-Committee
APPROVED 3/8/2016 VOID AFTER 3/17/2017
IRB# SW16-2 CHAIR [Signature]

INFORMED CONSENT
College of Social and Behavioral Sciences
School of Social Work

The study you are asked to participate is designed to explore future planning support for parents of adult children with intellectual/developmental disabilities. This study is being conducted by Patricia Lopez, under the supervision of Dr. Carolyn McAllister, Associate Professor of Social Work, California State University, San Bernardino. This study has been approved by the Department of Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

PURPOSE: The purpose of this study is to gain a better understanding of future planning support for parents of adult children with intellectual or developmental disabilities, and their experience with future planning services.

DESCRIPTION: In order to gain a better understanding of what supports are provided to parents of intellectually or developmentally disabled adults, an interview will be conducted with questions regarding current level of support, future anticipated supports and what would be helpful in regard to services.

PARTICIPATION: Your participation in this study is completely voluntary. You may refuse or stop your participation at any time without consequence.

CONFIDENTIALITY: Your identity will remain anonymous and you will be assigned a letter by the researcher prior to beginning the interview. All audio recordings will be destroyed after being transcribed by the researcher. All transcribed information will be kept in a secure, locked box.

DURATION: The demographic portion to be filled out will take approximately 5 to 10 minutes and the interview will be approximately 25 to 35 minutes in length. The total duration of this study will be 35 to 45 minutes.

RISKS: There are no foreseeable risks to participants in regard to this study.

BENEFITS: Participants will receive a 15 dollar Target gift card for their participation

CONTACT: If you have questions or concerns about this study, you may contact Ms. Lopez's research advisor Dr. Carolyn McAllister by phone (909) 537-5559 or by email at cmcallis@csusb.edu.

RESULTS: Results of this study may be obtained on CSUSB Scholar Works at California State University, San Bernardino at 5500 University Parkway, San Bernardino CA 92407.

This is to certify that I have read the above information and am 18 years or older.

Please place an "X" mark here

Date

I agree to be audiotaped (Please circle one): YES NO

909.537.5501

5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407 2393

APPENDIX C
DEBRIEFING STATEMENT

**Exploring Future Planning Support for Parents of Adult Children
with Developmental/Intellectual Disabilities
Debriefing Statement**

This interview you have just completed was designed to explore future planning supports for parents of adult children with developmental/intellectual disabilities. In this study there are many perspectives to consider in future planning for an adult child. While there can be many services for school age individuals, it is important to understand the needs of parents and their adult children in terms of services and future planning supports offered from agencies and social workers. I was interested in the perspective of parent care givers and wanted to understand their direct point of view to assess if future planning supports are being offered or if future planning would be beneficial.

Thank you for your participation and for not discussing the contents of the decision question with other students. If you have any questions about the study, please feel free to contact Patricia Lopez or Professor Carolyn McAllister at California State University, San Bernardino (909) 537-5559 or by email at cmcallis@csusb.edu.

If you would like to obtain a copy of the group results of this study, please contact Professor Carolyn McAllister at (909) 537-5559 or by email at cmcallis@csusb.edu at the end of Spring Quarter of 2016.

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